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**A qualitative exploration of the participants' experience of a web-based  
physiotherapy programme for people with multiple sclerosis (MS): Does it impact  
on the ability to increase and sustain engagement in physical activity?**

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24    **Abstract (196 words)**

25    **Background** Web-based exercise and physical activity interventions are being  
26    developed as a potential way to help people with multiple sclerosis achieve and  
27    maintain increased physical activity levels. Seeking feedback from people who  
28    have used such interventions will help guide the development process.

29    **Methods** In-depth interviews were used to explore the experiences of participants who  
30    used a web-based physiotherapy intervention as part of a feasibility randomized  
31    controlled trial. Interviews were audio-recorded, transcribed verbatim and analysed  
32    using thematic analysis.

33    **Results** Eleven people (age 28-68) were interviewed. Most perceived that their physical  
34    activity had increased, primarily due to completing twice-weekly web-based  
35    physiotherapy sessions. Three key themes were identified. ‘It’s all in one place’  
36    encompasses the value of having a convenient and portable program. ‘Keeping an eye’  
37    captures people’s thoughts regarding the supervision offered by the physiotherapist,  
38    through the website, and ‘Hopes and expectations’ reflects the importance of having  
39    opportunity to discuss what may be gained from using such a program.

40    **Conclusions** This intervention offered a convenient, flexible and portable  
41    physiotherapy program which most people perceived helped them achieve and  
42    sustain increased levels of physical activity. Talking with people about  
43    expectations is important, particularly if a person’s condition is deteriorating.

44    **Keywords:** exercise, rehabilitation, telerehabilitation, internet-based, e Health

## Introduction

Achieving and maintaining recommended levels of physical activity is important yet challenging for many people with multiple sclerosis (MS). The use of targeted exercise programmes and physical activity promotion have been demonstrated to lead to a range of physical [1, 2, 3, 4, 5] and emotional [6, 7] benefits which may also extend to minimizing the complications and comorbidities associated with living a more sedentary lifestyle [8]. This has encouraged an increased emphasis within clinical practice to incorporate targeted exercise programmes, and facilitate engagement with increased levels of physical activity [9]. In this study physical activity is considered in line with the Caspersen definition as ‘any bodily movement produced by skeletal muscles that requires energy expenditure’ [10] and as such enables participants to discuss all types of activity such as structured exercise and sport, but also lifestyle activity such as housework, gardening and employment.

Disease specific guidelines for people with MS [11] have helped guide physical activity prescription, particularly for those with mild to moderate disability, but the challenge to ensure adequate levels are sustained in the long term remains for individuals and those involved in their care. Current physical activity levels in people with MS remain low [12] and this concern has prompted research to identify factors that may have a positive influence on long-term participation. These include: choice of activity [13]; control over level of engagement; advice and support received; self-efficacy [14, 15] and use of goal setting [16]. Evidence also describes some of the barriers to participation that people with MS experience, such as the effort and travel distance required to access rehabilitation venues, fatigue and lack of time [17].

The use of technology, such as the internet as a mode of delivery of exercise and physical activity interventions, is being increasingly trialled in many areas of healthcare to address some of these barriers. Two systematic reviews evaluating a wide variety of telerehabilitation interventions in MS provide a broad overview of their content, design and outcomes. [18, 19] They suggest that this approach may be effective in increasing physical activity [18, 19] in the short term, although compliance remains a significant issue [20, 21, 22] and an important factor to further explore.

Telephone interviews [23] and process evaluation questionnaires [23, 24] have been previously used to explore the feasibility and acceptability of different web-based interventions and have provided researchers with areas of development on which to focus. Continuing to capture the user experience about issues broader than the operational aspects of the programme, is likely to provide a deeper understanding of the factors that impact on the use of web-based interventions and may be instrumental in their further development.

This study aimed to explore the user experience of a web-based intervention which was part of a multi-centre randomised controlled feasibility trial of web-based physiotherapy ((WEBPaMS), registered at ClinicalTrials.gov (Identifier: NCT02508961)), and specifically, whether or not users perceived that it had impacted on their ability to increase and sustain engagement in physical activity.

## **Materials and Methods**

### ***Ethical Approval***

Ethical approval for this study (15/WS/0030) was obtained from the West of Scotland Research Ethics Service, Glasgow. All participants gave written informed consent prior to taking part.

### ***Research Approach and Methodology***

A qualitative research approach was selected to address the aim of the study using a general qualitative inquiry design, underpinned by a pragmatic epistemology and a critical realism ontology. In-depth, individual, face-to-face interviews were undertaken with the participants allocated to the web-based programme at one of the three main WEBPaMS study sites (Plymouth). Interviews were selected to gain depth of understanding about each participant's unique experience of the intervention and in order to explore this in light of their own individual circumstances. They were conducted at the participant's home (or preferred venue) using an interview guide (table 1) which was developed and piloted with a person with MS who was unrelated to either this sub-study or the main WEBPaMS study. Open questions, with prompts as required, were used with sufficient flexibility to enable participants to raise issues they considered important. Interviews were conducted by the (female) primary researcher (RD, a PhD student and physiotherapist with 20 years clinical experience). Interviews lasted up to one hour, were audio recorded and transcribed verbatim. This study is reported in line with the COREQ guidelines [25].

**[Table 1 near here]**

### ***Participants and Intervention***

Each of the WEBPaMS [26] intervention group participants at the Plymouth site were invited to participate in this sub-study. The entire WEBPaMS sample was not investigated for pragmatic reasons. This study was undertaken as part of the primary researcher's doctoral work exploring adherence to physical activity and physiotherapy programmes and Plymouth was her location of residence. An invitation letter and participant information sheet were sent to the potential participants within one month of their final WEBPaMS follow-up assessment. Each gave consent and were interviewed within six weeks (range 1-6 weeks) of that final assessment. Inclusion criteria for the WEBPaMS study included; adults with a confirmed diagnosis of MS, known to an MS consultant in the study recruiting areas, an Expanded Disability Status Scale (EDSS) score of 4 - 6.5 (indicating mild to moderately impaired walking) and access to a personal computer/tablet or smart television with an email address and internet connection. Potential participants had been excluded if they were already taking part in regular exercise or physiotherapy (two or more times per week), had poor cognitive function as assessed by a Mini Mental State Examination Score (MMSE <24), had any significant change in medication or a relapse requiring treatment within the last 3 months, or any significant co-morbidities for which exercise was contra-indicated. They were also excluded if they were unwilling to be randomised to intervention/ control group or were currently participating in another clinical trial (rehabilitation or pharmacological).

The main WEBPaMS study was a single blind randomised controlled feasibility study. Ninety participants from three centres were randomised to receive either a six-month individualised web-based exercise programme (n=45) (intervention) or a paper based exercise programme (n=45) (active comparator). All participants were assessed by a

142 physiotherapist, had an individualised exercise programme devised and were asked to  
143 complete it twice weekly. A range of outcome measures were completed at baseline,  
144 three months, six months and nine months (three month follow up). The active  
145 comparator group received their exercise programme in paper format  
146 ([www.physiotherapyexercises.com](http://www.physiotherapyexercises.com)) and were asked to complete a paper exercise diary.  
147 The intervention group accessed their exercise programme via a website  
148 ([www.webbasedphysio.com](http://www.webbasedphysio.com)). The website included exercises in video format with  
149 audio and text description along with MS specific exercise advice. Participants were  
150 requested to complete a diary entry after every session to indicate which of the exercises  
151 had been completed and to comment on any issues such as if the exercises were too  
152 hard or easy. The physiotherapist remotely reviewed the diaries every two weeks and  
153 was able to modify the exercise programme in line with any feedback they had received.  
154 Participants were informed of any changes to their programme via email and could  
155 contact the physiotherapist through the diary or via email or telephone at any point if  
156 required. Further information regarding the intervention can be found in the pilot [23]  
157 and main study [26] publications.

### 159 ***Data Analysis and Ensuring Rigour***

161 Data were analysed using thematic analysis according to the six phase method of  
162 identifying and analysing patterns in qualitative data described by Braun and Clarke [27]  
163 using a general inductive approach. Initially the audio recordings of each interview were  
164 listened to twice and transcripts were read and re-read in order for the researcher to  
165 become familiar with the data. Observations were noted on the transcriptions as  
166 appropriate during this stage and relevant codes were generated along with appropriate



data extracts. The next stage of analysis involved the primary researcher considering and collating the codes by hand, rather than through use of a software package and making note of meaningful patterns in the data that were relevant to the research question. These were discussed with the other members of the research team (JF, LP and EC) on a number of occasions and used to create themes and subthemes that captured the essence of the participants' voice and worked in relation to the data set.

Themes and subthemes are presented using pseudonym quotes (with participant age and EDSS) to illustrate the participant view.

Rigour was enhanced during the process by ensuring an audit trail of the primary researcher's (RD) process. A second researcher (JF) independently coded and discussed in detail three of the transcripts with RD and the whole team was involved in reviewing each of the themes and subthemes. The principles of credibility, transferability and dependability were followed throughout [28]. Reflexivity was promoted by the primary researcher who is an experienced neuro-physiotherapist. Steps, such as completing a reflexive diary and regularly meeting with the research team were put in place to try and minimise the bias this would bring to interpretation of the data. A summary of the main themes was sent to participants for member checking. Responses indicated that the summary provided an accurate reflection of the interviews content.

## Results

Eleven out of a possible 12 people were interviewed. One person did not respond to the initial invitation letter or to three further attempts to make contact by letter, email and

telephone. Participants were 90% female with an age range 28- 68 years; time since diagnosis range 1-40 years and EDSS range 4-6.5. Disease course was: Relapsing Remitting [n=4], Primary Progressive [n= 1] and Secondary Progressive [n=6]. Three participants were employed, two unemployed and six were either retired or medically retired. Demographic information of participants is presented in table 2.

[Table two near here]

### ***Perceived impact on physical activity level***

Nine of the 11 participants felt that their physical activity levels had increased over the study period. This was attributed to a variety of reasons including improved balance, confidence and general fitness, increased motivation to exercise, and being committed to the study protocol of completing the exercise programme twice-weekly. One participant described an example of when she was more physically active which she attributed to the benefits she had experienced from engaging in the web-based programme.

“I picked up my daughter and we drove to [local town]; I got lost on the way but we got there. It took ages to get there... we walked all the way round [local town]. Oh my God. It is like really narrow, there’s that little high street. So I had to walk up there. I probably stopped about three times. That’s good for me. That is really good for me and that’s quite a steep road and I made it all the way to the top.” *Debbie (age 45, EDSS 5.0)*

Further exploration of the potential reasons for her improvement revealed that completing her exercise programme had helped her to feel fitter and be able to achieve more, which in turn provided motivation to continue.

Well that's [using web-based physio] what started me off isn't it? I wouldn't have bothered otherwise, would I, so yeah, I wouldn't honestly truthfully I wouldn't have bothered. That's what made me get up and go, "what, I can do it!"

*Debbie (age 45, EDSS 5.0)*

Not everyone felt that their activity levels improved however. Two participants shared their thoughts regarding the impact that disease progression had had over the duration of the WEBPaMS study. Both noted a deterioration in their activity level, with one person, to the point that she was no longer able to walk. In this case the participant explained that although she was now not walking, having been able to make direct contact with the physiotherapist by reporting her difficulties on the online diary page, she was able to seek advice early, have her exercise programme modified and was enabled to continue to exercise at a level she could manage. Without this, when her primary activity (walking) was no longer possible she would have had to contact her doctor and wait for referral for a physiotherapy appointment to discuss her situation. The participant's perception was that the programme helped her to be more active than she would otherwise have been and noted that it was the timely remote support through the intervention that had facilitated this.

Things had got to the point that I wasn't able to take my son to school, a friend was picking him up and another friend bringing him back because I was finding

it too difficult to walk... so I was glad to have the exercise programme as well to make up for the lack of exercise that I was getting by not doing the school run, so that was quite good. *Becky (age 54, EDSS 6.5)*

Only two of the nine participants who perceived that their physical activity levels had improved described this in terms of walking further or more frequently. The majority reported that they had increased physical activity by completing the two web-based exercise sessions in addition to their usual weekly activity.

### ***Themes and subthemes.***

Three key themes were identified from the participant experience data with specific regard to perceived impact on physical activity. They are: (1) “It’s all in one place”, (2) “Keeping an eye” and (3) “Hopes and expectations”. Subthemes were also developed, some of which were linked to more than one of the themes.

#### ***Theme 1 “It’s all in one place”***

“It’s all in one place” encompasses the value placed on having an easily accessed, portable and flexible individualised exercise programme. These benefits were reported as important in helping participants use the intervention regularly, which in turn facilitated the increased physical activity they described.

#### ***Subtheme: Accessibility***

Five participants reported that the ease of accessibility provided by having their exercise programme accessed on their electronic device (e.g. computer, tablet, or phone) made it much more convenient. This meant they were more likely to complete their programme, and in turn increase their physical activity that day. One participant [Hannah (age 28, EDSS 5.5)] commented: “the web is part of my life”, reflecting that she used her electronic devices regularly.

Additional reasons were reported as to why ease of access was a benefit to participants. One participant described previous experience of having written paper exercise programmes, which on occasions she had lost. She noted that having the program in one place (on her computer) not only meant she didn’t have to worry about losing it, she had the added benefit of not having to physically struggle around the house to find where she had put it.

I just find it quite difficult to manage lots of bits of paper which seems silly but I do, so having it online actually I found easier way to keep on track with it...papers do easily get lost, or dog-eared, or thrown away by mistake so it was good to have it all on computer in one place so you always know where your laptop is... Because it’s there and easier to find and you’re not faffing [colloquialism, struggling to get things together] around because of not being able to move very easily, I don’t know, you value it more in a way.

*Becky (age 54, EDSS 6.5)*

In some cases, when using their electronic device as part of their daily life, simply seeing the link website address to web-based physio prompted access to the site and completion of their exercise programme.

Well, if I'd have had a bit of paper and there wasn't the incentive to look on the website and um you know, I am fairly computer literate and I use the computer a lot and then you know it just becomes second nature to check and um and if I hadn't had that incentive it would have just been a bit of paper exercises I'd have put them or pinned them up on the wall and um then said oh I better do some exercises today as an after-thought. It wouldn't have been at the front of my mind... When I am on the computer, I see that and it incentivises me.

*Simon (age 63, EDSS 6.5)*

One person reported that seeing the website link on her iPad motivated her to get out and walk more, so increasing her overall level of physical activity. At no point other than the very start of the study did she choose to access her web-based physio programme on the website. For her, simply the visual prompt to exercise played a significant role.

I've done a little bit more walking um, perhaps like popped into town on a day when I wouldn't have normally gone into town because I've seen it [the website link] and I've thought "oh, yeah, you know, I'd like to do that today" that's kind of helped me; reminded me to do some exercise... rather than sitting there like perhaps going on Facebook or something, going "well it's actually quite sunny and nice today, go out and take a walk".

*Hannah (age 28, EDSS 5.5)*

One aspect of the programme that some participants were less positive about was being asked to complete the online exercise diary to show what exercises had been done. Although the purpose was to enable the physiotherapist to remotely monitor and progress the exercise programme this was not always completed, especially as people became more familiar with their exercises and did not rely as much on this aspect of the intervention. Two participants commented that once they had got to a stage where they were confident with their exercise programme, they did not feel the need to access the website and as such it would have been helpful to have been able to go back to the website and add comments retrospectively rather than every time. These views were also reported by some of the participants who took part in exit interviews following the main study as part of the process of exploring the intervention feasibility and acceptability. [26]

Sometimes I did feel it was a bit annoying having to go back and do the ticking when you'd done your exercises like "oh right! Yes, need to do that part" as well so sometimes it could be a bit of a nuisance to think you had to do the filling in as well.

*Becky (age 54, EDSS 6.5)*

The vast majority of the participants reported the intervention was easy to access however one noted difficulties setting up a link on her computer and suggested having an app to click on would have been easier.

When I first started going on it I kept forgetting what the web address was and I kept having to go into the, I think it was in the email to the link to get on it cuz I couldn't remember what it was.

Debbie (age 45, EDSS 5.0)

#### **Subtheme: Flexibility**

The opportunity to choose when and where to access the website was also reported as a benefit of this approach to delivering physiotherapy programmes. Some people reported a preference to exercise in the privacy of their own home where they didn't experience embarrassment they had previously felt when exercising in front of others. In addition, flexibility in terms of exercising at a time that fitted with family life or around the presence of symptoms was described.

If I was doing it in a group session, I would be conscious of being clumsy and messing up and something like that. At least at home, I am more comfortable at doing it at my own pace and my own way and then monitoring it. So I feel better doing it that way.

*Simon (age 63, EDSS 6.5)*

I don't particularly want to be part of a group um, I'm much happier doing at my own level and my own pace really um, and so that was good for me and it was good for me because I'm reasonably computer literate so it was easy, I did it on my phone.... It's difficult for me, not physically, to get to the same place regularly in the course of a week cos I just find work's quite, encroaches on my free time and also the children.

*Sarah (age 51, EDSS 4.0)*



Literature suggests that to achieve the potential benefits of exercise, people with MS should be completing exercises at a challenging level [29]. For some people, the web-based programme provided an opportunity to exercise in a safe and familiar environment where they felt able to challenge themselves and perhaps achieve increased benefits.

I was in familiar surroundings, so I was able to push myself a bit more as well because of the surroundings I felt happy in my home... I knew where things were. You know, I did have wobbles when I was doing them [balance exercises] but it was great because I knew where everything was, so I could stop myself... whereas if I was doing that in a group and especially if I'd been in the middle of a group somewhere or something I'd have been right down on the floor. I didn't have to think, "oh I have to make the effort or I have got to make myself look presentable before I go out the door". I could just you know be in my jimjams [colloquialism pyjamas] if I wanted to do it, which was great, you know, it didn't really matter, you know. If I couldn't do one for any reason, or did it stupidly, or lost my balance or anything, it wasn't a problem because I was at home.

*Emily (age 48, EDSS 6.0)*

For another participant, the flexibility of being able to exercise at home and with her children, was an important factor that helped her remain motivated to exercise.

Me and my littlies [colloquialism, children], because they love exercising, they're really sporty and they've done it with me before when I've been upstairs in the bedroom and I've had it on and they've been doing exercises with me so they give me more incentive to do it then because they want to do it, "oh do your exercises mummy!"

*Debbie (age 45, EDSS 5.0)*

In contrast, others reported missing the rapport and social aspect of exercising with others.

I did miss the action of the [local MS exercise group], I do like the interaction with the group, it's the social side as much as anything isn't it?

*Mary (age 61, EDSS 6.0)*

There's nothing negative about it apart from the fact that it's just not social is it?

*Debbie (age 45, EDSS 5.0)*

As such, it is perhaps the flexibility in choice of environment in which to exercise which is important. Facilitating choice of exercise was also reported as a benefit by some participants who liked being able to choose from their individualised programme which exercises to do and when (perhaps encouraging self-management and reflection).

### ***Subtheme: Portability***

Portability was an issue raised as a benefit by three people. They each described situations where they had been able to continue using their exercise programme when

working away from home or travelling on holiday. Each suggested that their programme worked well away from the house and that they would have been much less likely to have chosen to take a paper exercise programme with them.

You can take it with you because it's on your phone, and the first time I did it I put it on the iPad and we went away for the weekend and I thought it was great because I could do it, take it with me. It's been to Malta.... Tenerife, been to France.

*Wendy (age 60, EDSS 4.0)*

Having the website there, like I said at the beginning, is an incentive, whereas if you see a physio, you see the physio for a period and then you are left to go away and then it is up to you to ring them up again if you want more help and then again it is difficult to get appointments. It is accessible wherever I am. So even if you are travelling you can still access it.

*Simon (age 63, EDSS 6.5)*

## *Theme 2: "Keeping an eye"*

There were mixed views regarding the type and level of remote support provided by the physiotherapist through the website. Around half of the participants felt it was sufficient, suggesting that the support enabled discussion and progression of their exercise programme and potentially facilitated longer-term engagement with it.

I liked the fact that someone was keeping an eye so I wasn't doing something stupid [exercise technique] that, you know, I shouldn't have been doing, and also so that I knew that I would carry on doing it.

*Mary (age 61, EDSS 6.0)*

I always knew if I wanted to change something, all I had to do was contact the physio or write something in [the online diary] and they would respond. I'm quite independent in that way [choosing and modifying exercises], maybe that doesn't work for everybody but I think I'm quite, er, self-critical, you know, I can appraise what I'm doing quite well, quite honestly I think.

*Sarah (age 51, EDSS 4.0)*

Others however did not feel that the support was sufficient to keep them engaged and resulted in them only accessing the site for four of the possible six months.

[I needed someone] saying "Debbie, get on the website, you're doing really well, you need to exercise, don't give up". I'm one of those that needs a push all the time; that's the sort of person I am. It's the contact isn't it, it's the interaction I suppose [that wasn't enough].

*Debbie (age 45, EDSS 5.0)*

One person discussed the importance of building a relationship with someone who could support and encourage them to continue to be active long-term. Her experience was that this did not happen for her through the website.

When you're having like regular [face to face] physio more often, I think you're more likely to, or I personally am more likely to engage in your activities because you're, you're being reminded on a weekly basis by a, by a physio.. but when you're not seeing a physio so often, it's hard to self-motivate yourself to do your exercises. *Hannah (age 28, EDSS 5.5)*

A related issue raised by three participants was that of the website allowing immediate access to a physiotherapist for advice regarding difficulties with an exercise or symptom. Each described previous experience of having to wait a considerable length of time to see a physiotherapist.

If you see a physio, you see the physio for a period and then you are left to go away and then it is up to you to ring them up again if you want more help and then again it is difficult to get appointments. *Simon (age 53, EDSS 6.5)*

Yeah some people would prefer that they don't have [only remote support] waiting perhaps several months for an appointment so they can have face to face contact. But for other people who are maybe more disabled and can't get there so easily or are perhaps working and haven't got the time they could just have a quicker contact with the physio. *Claire (age 65, EDSS 6.0)*

The most frequently reported aspects of the website that participants found helpful were the exercise videos, (in line with the pilot study [23]), and the opportunity to email for advice. This support enabled some participants to continue exercising without the need for face-to-face contact throughout the study.

488

489 I think it's okay with the computer because as I say the videos are there for you  
490 to watch. If you didn't have that and you just had it written down as a diagram  
491 you might want to see the physio more in order that they could demonstrate to  
492 you what you are supposed to be doing. *Claire (age 65, EDSS 6.0)*

493

494 Further thoughts from participants suggested the potential benefit of such a system to  
495 the clinician, who could oversee and maintain close contact with many more patients  
496 rather than relying on face-to-face assessments.

497

498 It would free up more time for the physio to see other people as well if they  
499 weren't constantly needing to have an appointment that lasted half an hour or  
500 something. If they could just be in touch with the person that had a problem they  
501 might be able to deal with it in five minutes rather than half an hour. They might  
502 know straight away what the problem is and say just do it this way instead and  
503 then it could be sorted out. I think it would free up their time more.

504 *Claire (age 65, EDSS 6.0)*

505

### 506 *Theme 3: Hopes and Expectations*

507

508 This particularly challenging theme highlighted that clinicians and researchers need to  
509 openly discuss and better understand people's hopes and expectations of the potential  
510 benefits of exercise and physical activity for them. Sarah described the emotional  
511 impact that not achieving what she had hoped for during the study.

512

513 If I'm being brutally honest with myself, I think I've gone down even though  
514 I've been working quite hard and that has been quite hard [emotionally] I think.  
515 I think I'm quite good at burying my head in the sand...I didn't expect to feel  
516 the way I felt when I started doing it. I didn't expect that to be the way I would  
517 be feeling at say six, seven, eight months...maybe it's because I was coming to  
518 the end [of the study] and I haven't achieved what I thought I might.

519 Sarah (age 51, EDSS 4.0)

520  
521 One participant in particular clearly explained how disappointed she was in not seeing  
522 the improvements she had hoped for and how this had affected her motivation to  
523 continue. She challenged clinicians to consider how to manage her expectations more  
524 effectively.

525  
526 I thought that by doing the exercises I'd build up some stamina and I wouldn't  
527 have noticed it [fatigue] quite so much... but it was the fatigue... that was the  
528 annoying bit if you like, you know, I had hoped that I'd go through a barrier and  
529 come out the other side. I think it's the nature of the beast, perhaps it was my  
530 expectations that needed to be managed... because I carried on with it and did  
531 everything, but....I always feel that I could be doing more, and then on some  
532 days when I try and do more I get disappointed because I haven't actually been  
533 able to do it. And I don't know whether that's because I'm judging myself on  
534 too high a standard or whether somebody should be behind me going "go on",  
535 "keep on".... "Am I giving in to this?" "Should I be going that extra mile?"  
536 ...do you know what I mean, how, how far do you push yourself?

537 Mary (age 61, EDSS 6.0)

538

539 In contrast, being motivated to exercise and walk more in one case, and stick to, and  
540 progress their web-based programme in another, helped two participants exercise  
541 beyond their own hopes and expectations.

542

543 ...it's um the like a rewarding process that when you get home you're like  
544 "actually I've done this today, I've walked this far" rather than just, kind of like,  
545 staying at home and perhaps watching something on tele so it's, it's been, yeah  
546 it, it's been quite nice actually. Hannah (age 28, EDSS 5.5)

547

548 I've got the feeling that I'm actually doing more than I thought I could do.

549 Wendy (age 60, EDSS 4.0)

550

551

## 552 Discussion

553

554 The purpose of this research was to explore the user experience of the web-based physio  
555 intervention and further, whether or not participants perceived it had impacted on their  
556 ability to increase and sustain engagement in physical activity. The interview data  
557 demonstrated that the majority of participants felt that the intervention had helped them  
558 achieve increased physical activity levels, typically by the addition of the twice-weekly  
559 web-based exercise sessions. This perception of having increased physical activity  
560 levels contrasts however with the objective accelerometry data from the main study  
561 which demonstrated a decline in steps per day over the nine month study period. [26]  
562 Such disparity between self-report and objective measures is well reported [30] and



underlines the complexity of this issue, particularly in a progressive condition such as MS where physical activity levels fluctuate and where people's perspectives are constantly recalibrated as they adjust expectations within their changing context.

It is important to consider the role that factors other than the intervention itself may have played when considering perceived increase in activity. Some participants in this sub-study reported that it was their commitment to the study that was the motivator. However, having not interviewed the active comparator group participants it is not possible to know whether committing to the study provided a positive influence on their exercise behaviour. Further research is required to better understand this.

Some strengths of this study are that it sought the experiences of people with all MS disease types and that of those with moderate as well as mild disability. Participants reported a variety of experiences of the intervention that do not appear to be related to disability level or indeed age, as demonstrated by the quotes from participants across the age spectrum ( 28, 54 and 63 years) regarding the accessibility of this intervention. The different opinions represented in this study highlight the importance of acknowledging that a variety of models of service delivery may be required to meet differing needs. Further, that discussing with people their preferences with respect to intervention and delivery type within the constraints of health service funding challenges is crucial.

In the first theme “All in one place”, the subthemes of accessibility, flexibility and portability describe some of the benefits that participants in this study felt they gained from this intervention and go some way to address some of the reported barriers to exercise [13, 15, 17]. The qualitative data supports the notion that the intervention made it easier for some people to integrate regular exercise into their daily lives. The accounts of the participants also suggest that this mode of exercise programme delivery may be particularly helpful for people who are technology literate, value flexibility in terms of location, time of day and choice of exercise, and who are confident to exercise at a challenging level independently. It may be that the ability to modify and progress exercise programmes online result in these interventions being better able to deliver the ongoing change and challenge that is required to achieve positive clinical outcomes. This is yet to be determined in a definitive randomised controlled trial.

“Keeping an eye” was the second theme identified. For an intervention such as this to be effective in supporting people to be more physically active long-term, it is important for people to remain engaged. In this study, some participants reported that having their exercise diary monitored remotely and receiving timely support from the physiotherapist were important in maintaining adherence. Although each participant’s web-based programme was reviewed every two weeks, the amount of support each individual received depended upon the feedback they provided via their online diary, email or telephone. It is likely that this will have influenced their experience of the supervision received. Other studies describing the development of a different web-based intervention have demonstrated an improvement in adherence by the addition of video coaching sessions [24, 31, 32].

Whilst the views expressed by our participants regarding satisfaction with the level and type of support provided were mixed, with those most satisfied tended to also describe feelings of confidence in self-managing their condition. It appears that this intervention helped some people develop the confidence to exercise at a challenging level. Results from a nominal group study conducted as part of the development of a balance, safe mobility and falls management programme for people with multiple sclerosis [33] identified that people may need significant encouragement and support to develop the confidence to undertake highly challenging balance exercise. For some people, this intervention may have facilitated this.

The important issues regarding the theme “hopes and expectations” draw focus on how best to support people with MS to be as physically active as possible. For some people this may be to achieve improvements such as getting fitter, walking further or gaining confidence but for others achievement may be in terms of minimising the effects of disease progression on mobility. It is therefore imperative that clinicians and researchers attend to this range of expectations and consider carefully choice of outcomes when establishing programs such as this. In this study, some participants described the disappointment, frustration and distress experienced by not meeting their own, or what they perceived to be the clinician’s expectations. Similar issues were raised in other explorative studies in people with MS. One [34], in relation to a gaming intervention where some participants reflected negatively on their physical abilities and limitations in light of Nintendo Wii Fit feedback, and a second [35] evaluating a physical activity programme, where issues of disappointment and frustration were described concerning the way in which their MS prevented them from being able to engage in pre-morbid activities. It is likely that on some occasions in this study, discussion regarding the

expectations of the intervention by both the person with MS and the physiotherapist would have highlighted differences that could have been talked through and may not have led to the individuals becoming disappointed and demotivated by their lack of improvement.

Effective strategies are required to enable honest and open discussions especially when introducing the idea of exercise and its benefits to people with progressive disease. This is a key clinical area that warrants further exploration.

## **Limitations**

There are a several limitations of this study. Firstly, participants knew the primary researcher (RD) through her role as the Plymouth site WEBPaMS intervention physiotherapist. This potentially may have resulted in participants feeling they needed to share experiences that were more positive. Secondly, all of the researchers are physiotherapists which will have influenced the reading and interpretation of data. Every attempt was made to explore all participant experiences through use of the interview guide and ensure the trustworthiness and credibility of the interpretation of the data by using several strategies to ensure decisions could be evaluated and defended [36]. Thirdly, only intervention group participants at one site were interviewed in this study as it was conducted as part of the doctoral work of the primary researcher. There is no reason to suggest however that there would be notable differences in data from either of the other two sites, and this was confirmed by the results of the process mapping exercise, which was undertaken as part of the feasibility trial. [26] Because the

aim of the study was to explore user experience of the web-based physio intervention only intervention group participants were interviewed. Finally, the small numbers of participants in this study has the potential to limit its findings, however, the last two interviews did not add new themes to the data and as such, it is likely that data saturation had been reached.

## **Conclusion**

The findings of this study demonstrate that most of the participants, perceived that the web-based physio had facilitated an increase in their day-to-day physical activity. Also highlighted is the importance of building in conversations with people with MS about expectations of exercise and its potential benefits, particularly for those whose condition is deteriorating. Finally, it is important to consider who will benefit most from a remotely delivered and monitored exercise programme such as web-based physio. This data suggests that the target population may be those who are technology literate (or have a significant other who are), value the flexibility that such interventions can offer, prefer to exercise independently in an environment of their choice and have confidence and skills to self-manage without face to face contact.

## **Declaration of Interest**

The authors report no conflict of interest

6614 words

## **References**

- 686 1. Kjølhede T, Vissing K, Dalgas U. Multiple sclerosis and progressive resistance  
687 training: a systematic review. *Mult Scler* 2012;18:1215–1228.
- 688 2. Pearson M, Dieberg G, Smart N. Exercise as a therapy for improvement of  
689 walking ability in adults with multiple sclerosis: a meta-analysis. *Arch Phys Med*  
690 *Rehabil.* 2015;96:1339–1348.
- 691 3. Pilutti L, Greenlee T, Motl R, et al. Effects of exercise training on fatigue in  
692 multiple sclerosis: a meta-analysis. *Psychosom Med* 2013;75:575–580.
- 693 4. Platta M, Ensari I, Motl R, et al. Effect of exercise training on fitness in multiple  
694 sclerosis: a meta-analysis. *Arch Phys Med Rehabil.* 2016;97:1564-1572.
- 695 5. Snook E, Motl R. Effect of exercise training on walking mobility in multiple  
696 sclerosis: a meta-analysis. *Neurorehabil Neural Repair* 2009;23:108-116.
- 697 6. Adamson B, Ensari I, Motl R. The effect of exercise on depressive symptoms in  
698 adults with neurological disorders: a systematic review and meta-analysis. *Arch Phys*  
699 *Med Rehabil* 2015;96:1329–1338.
- 700 7. Ensari I, Motl R, Pilutti L. Exercise training improves depressive symptoms in  
701 people with multiple sclerosis: results of a meta-analysis. *J Psychosom Res*  
702 2014;76:465–471.
- 703 8. Motl RW, Fernhall B, McAuley E, et al. Physical activity and self-reported  
704 cardiovascular comorbidities in persons with multiple sclerosis: evidence from a cross-  
705 sectional analysis. *Neuroepidemiology.* 2011;36(3):183-91.
- 706 9. Motl R. Lifestyle physical activity in persons with multiple sclerosis: the new  
707 kid on the block. *Mult Scler.* 2014;20(8):1025-9.
- 708 10. Caspersen C, Powell K, Christenson G. Physical activity, exercise, and physical  
709 fitness: definitions and distinctions for health-related research. *Public Health Rep.*  
710 1985;100(2):126-131.

- 711 11. Latimer-Cheung AE, Martin Ginis K, Hicks A, et al. Development of evidence-  
712 informed physical activity guidelines for adults with multiple sclerosis. *Arch Phys Med*  
713 *Rehabil.* 2013;94(9):1929-36.
- 714 12. Klaren RE, Motl RW, Dlugonski D, et al. Objectively quantified physical  
715 activity in persons with multiple sclerosis. *Arch Phys Med Rehabil.* 2013  
716 Dec;94(12):2342-8
- 717 13. Hale L, Smith C, Mulligan H, et al. "Tell me what you want, what you really  
718 really want...":asking people with multiple sclerosis about enhancing their participation  
719 in physical activity. *Disabil Rehabil.* 2012;34(22):1887-1893.
- 720 14. Streber R, Peters S, Klaus P. Systematic review of correlates and determinants  
721 of physical activity in persons with multiple sclerosis. *Arch Phys Med Rehabil.*  
722 2016;97(4):633-645.
- 723 15. Plow M, Finlayson M. Exploring physical activity behaviour of persons with  
724 multiple sclerosis: a qualitative pilot study. *Disabil Rehabil.* 2009;31(20):1652-1665.
- 725 16. Casey B, Coote S, Shirazipour C, et al. Modifiable psychosocial constructs  
726 associated with physical activity participation in people with multiple sclerosis: a  
727 systematic review and meta-analysis. *Arch Phys Med Rehabil.* 2017;98(7):1453-1475
- 728 17. Kayes N, McPhearson K, Taylor D, et al. Facilitators and barriers to engagement  
729 in physical activity for people with multiple sclerosis: a qualitative investigation.  
730 *Disabil Rehabil.* 2011;33(8):625-42.
- 731 18. Khan F, Amatya B, Kesselring J, et al. Telerehabilitation for persons with  
732 multiple sclerosis. *Cochrane Database of Systematic Reviews.* 2015;4 CD010508
- 733 19. Rintala A, Hakala S, Paltamaa J, et al. Effectiveness of technology-based  
734 distance physical rehabilitation interventions on physical activity and walking in

- multiple sclerosis: a systematic review and meta-analysis of randomized controlled trials. *Disabil Rehabil.* 2016;1-15.
20. Dlugonski D, Motl RW, McAuley E. Increasing physical activity in multiple sclerosis: replicating Internet intervention effects using objective and self-report outcomes. *J Rehabil Res Dev.* 2011;48(9):1129-36.
21. Motl RW, Dlugonski D, Wojcicki TR, et al. Internet intervention for increasing physical activity in persons with multiple sclerosis. *Mult Scler J.* 2011;17(1):116-28.
22. Tallner A, Streber R, Hentschke C, et al. Internet-Supported Physical Exercise Training for Persons with Multiple Sclerosis-A Randomised, Controlled Study. *Int J Mol Sci.* 2016 Sep 30;17(10):1667.
23. Paul L, Coulter EH, Miller L, et al. Web-based physiotherapy for people moderately affected with Multiple Sclerosis; quantitative and qualitative data from a randomized, controlled pilot study. *Clin Rehabil.* 2014;28(9):924-935.
24. Dlugonski D, Motl RW, Mohr DC, et al. Internet-delivered behavioral intervention to increase physical activity in persons with multiple sclerosis: sustainability and secondary outcomes. *Psychol Health Med.* 2012;17(6):636-51.
25. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care.* 2007;19(6):349-357.
26. Paul L, Renfrew L, Freeman J, et al. Web-based physiotherapy for people affected by multiple sclerosis: a single blind, randomized controlled feasibility study. *Clin Rehabil.* 2018 Dec 4:269215518817080
27. Clarke V, Braun V. Teaching thematic analysis: Over-coming challenges and developing strategies for effective learning. *The Psychologist.* 2013;26(2):120-123.



28. Guba E, Lincoln Y. Fourth Generation Evaluation. Newbury Park, CA: Sage; 1989.
29. Gunn H, Markevics S, Haas B, et al. Systematic Review: The Effectiveness of Interventions to Reduce Falls and Improve Balance in Adults with Multiple Sclerosis. *Arch Phys Med Rehabil*. 2015 Oct;96(10):1898-912.
30. Motl, R. W, McAuley E, Snook, E. M. Physical activity and multiple sclerosis: a meta-analysis. *Mult Scler J* 2005 11(4): 459-463.
31. Motl RW, Dlugonski D. Increasing physical activity in multiple sclerosis using a behavioral intervention. *Behav Med*. 2011;37(4):125-31.
32. Pilutti LA, Dlugonski D, Sandroff BM, et al. Randomized controlled trial of a behavioral intervention targeting symptoms and physical activity in multiple sclerosis. *Mult Scler J*. 2014;20(5):594-601.
33. Gunn H, Endacott R, Haas B, et al. Developing a falls management intervention for people with MS: A nominal group study. *Mult Scler J*. 2015:492-534.
34. Plow M, Finlayson M. A Qualitative Study Exploring the Usability of Nintendo Wii Fit among Persons with Multiple Sclerosis. *Occup Ther Int*. 2014;21(1):21-32.
35. Dixon-Ibarra A, Nery-Hurwit M, Driver S, et al. Using health promotion guidelines for persons with disabilities to develop and evaluate a physical activity program for individuals with multiple sclerosis: A feasibility study. *Eval Program Plann*. 2017 Apr; 61:150-159.
36. Miles M, Huberman A, Saldana J. *Qualitative Data Analysis: A Methods Sourcebook*. Vol. 3rd ed. London: Sage Publications; 2013.

**Table 1: Interview guide**

<p><b>It has been a little while since you finished using the web based physiotherapy programme... perhaps you can start by telling me what you thought of it?</b></p>
<p><b>Have you seen a physiotherapist before?</b></p> <p>Prompt: One-to-one? Exercise programme? Group? National Health Service?</p> <p><b>Did web-based physiotherapy differ? How? Why?</b></p>
<p><b>As part of the WEBPaMS study you were asked to follow your programme twice a week. Did you find you could stick to that?</b> Prompt: What stopped/ helped you?</p>
<p><b>Did you manage to do any other physical activity as well as this?</b></p> <p>Prompt; What do you do? Day to day routine? Around the house/ elsewhere?</p>
<p><b>Has using the web-based programme made any difference to how active you are now?</b></p> <p>Prompt: compare with activity prior to starting the programme i.e. what did you do day to day? Exercise/ general activity? At home? Out and about? What do you think may have affected this?</p>
<p><b>Do you imagine using the website long term?</b></p> <p>Prompt- key points in condition/ stepping stone/ with/out online support</p>
<p><b>Is there anything else you like to tell me about your experience of web-based physio?</b></p>

Table 2: Demographic information of interview participants (n=11)

<b>Participant pseudonym</b>	<b>Gender</b>	<b>Age</b>	<b>EDSS</b>	<b>Disease course</b>	<b>Employment status</b>
Mary	F	61	6.0	SPMS	Part time employed
Hannah	F	28	5.5	RRMS	Unemployed
Debbie	F	45	5.0	RRMS	Unemployed
Simon	M	63	6.5	SPMS	Retired/ medically retired
Becky	F	54	6.5	SPMS	Retired/ medically retired
Fay	F	68	6.5	SPMS	Retired/ medically retired
Wendy	F	60	4.0	RRMS	Part time employed
Claire	F	65	6.0	SPMS	Retired/ medically retired
Emily	F	48	6.0	RRMS	Retired/ medically retired
Jane	F	59	4.5	SPMS	Retired/ medically retired
Sarah	F	51	4.0	PPMS	Part time employed

Legend: EDSS = Expanded Disability Status Scale; F = female; M = male; RRMS = relapse remitting multiple sclerosis; SPMS = secondary progressive multiple sclerosis; PPMS = primary progressive multiple sclerosis